



Strategies for Communicating with Individuals with Alzheimer's and Memory Loss:

Meeting their needs in special needs shelters

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Part 1: Understanding Alzheimer's, Cognitive Loss and Behaviors



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Dementia vs. Alzheimer's

- Dementia is not a disease
- Dementia is a group of symptoms characterized by confusion, memory loss and disorientation.
- Alzheimer's is the most common cause of dementia



Common Dementias

- **Alzheimer's**
 - Short term memory loss and cognitive decline
- **Lewy Body**
 - Hallucinations
 - Parkinson like symptoms
 - Fluctuating memory loss
- **Vascular**
 - Mini-strokes, stair step decline
- **Frontotemporal**
 - Loss of impulse control and social etiquette



Cognitive Losses Caused by Dementia

- Logical thinking
- Problem Solving
- Reasoning
- Learning
- Abstract thinking
- Memory
- Decision making
- Judgement



Cognitive Losses Caused by Dementia

- Language
- Reading/comprehension
- Speech- word finding
- Attention/concentration
- Sequencing
- Orientation to time & space
- Changes in personality



Challenges of Alzheimer's

- Don't assume that just because they look fine, they are
- Realize the patient can no longer save memories
- The patient lives in the moment
- Redefine success
- Don't take it personally
- No two Alzheimer's patients are alike



Primary symptoms

1. Memory loss- forgetting recently learning info, meals, names
2. Repeating stories or questions
3. Language problems
4. Misplacing objects
5. Difficulty performing tasks, learning new tasks
6. Orientation to time and space
7. Poor judgment and decision making
8. Problems with mental tasks- math, reading, writing
9. Changes in mood or personality- fearful, confused, suspicious
10. Increased dependency on someone else

Difficult behaviors

Agitation:

Physical: need to walk, wandering, pacing

Verbal: complaints, requests for attention, screaming

General: restlessness, irritability, antsy, fidgety

Aggression:

A hostile physical or verbal behavior.

Physical: hitting, pushing, kicking, scratching, biting

Verbal: threats, accusations, name-calling, obscenities

Difficult behaviors

Hallucinations:

- Hallucinations involve the senses. The patient may hear, see or feel things that are not there.

Delusions:

- Delusions are belief in something that is not true.



Difficult Behaviors

Paranoia:

Unrealistic blaming beliefs. The patient may think someone is poisoning him or is talking about him.

Illusions:

Misinterpreted images or visuals

Other Behaviors

- Wandering
- Elopement
- Sundowning
- Inappropriate behaviors and verbal comments
- Demanding to go home
- Pacing
- Sexual behaviors



Part 2. Behavior Management and Communication Strategies



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Don't assume

- Don't assume anything!
- Don't assume they know where they are
- Don't assume they know why they are there
- Don't assume they know who you are
- Don't assume they remember anything you have said, even if it was only five minutes ago
- Don't assume they remember the rules
- Don't assume they can read the signs



Responding to Behaviors

- Don't argue
- Don't use logic or reasoning
- Don't correct them
- Don't give lengthy answers and explanations
- Don't overwhelm them- people, questions
- Don't escalate the situation



Communication Approaches

- Limit open ended questions, use multiple choice and yes/no
- Complement, not question
- Provide reassurance **OFTEN**
- Get down at eye level
- Introduce yourself each time
- Focus on the behavior you want, not the behavior you don't want
- Avoid logic, explanations and lengthy answers



Responding to Challenging Behaviors

- Behaviors are a sign- they are trying to convey an unmet need
- Respond to the emotion first not just the behavior
- Speak calmly, clearly and slowly
- Your goal is to deescalate the situation
- Therapeutic fibbing
- Learn how to enter their reality
- Try to gently move them away from others
- Try to redirect them or go for a walk to a quieter area.



Strategies for Managing People with AD in shelters

- Have a way to identify individuals with Alzheimer's- bracelet, lanyard, purple vest
- Routine toileting, hydration, snacks, and walks
- Singing or calming music if possible
- Movable walls/partitions to enclose an area for people with Alzheimer's
- Quiet time periods during the day to allow for napping

Strategies for managing PWD in shelters

- Optimal strategy would be having designated AD specialists or trained volunteers there monitoring the individuals with Alzheimer's. Be proactive and not just reactive
- The special needs shelters provides medical personal to deal with medical needs of those with other diseases, they need to provide Alzheimer's trained staff/volunteers to meet the needs of the Alzheimer's patients.
- By having someone monitor them, potential problems can be detected before they become critical incidents.



**Part 3. Understanding the effects of
the shelter on the patient and
caregiver**




Effect of the Shelter on the person with AD

- Unfamiliarity and over stimulation of the shelter can increase confusion, disorientation, behaviors and fear
- Over stimulation of the noise, crowd and chaos can cause agitation and possibly aggressive behavior
- Other behaviors may include paranoia, anger, distrust
- They may take on the emotions of those around them
- Their reactions to the shelter environment may be new and surprising to the caregiver



Understanding the AD Caregiver in a Shelter

- Anxious- about weather, their house, their loved one, their health, their family, situation etc.
 - Distraught and unable to cope with the situation; Confused, disoriented and exhausted
 - Stress and anxiety- can affect their health and intensify problems
 - Unable to meet the needs of their loved one and difficulty dealing with their loved one's behavior
 - May be overwhelmed and surprised at new behaviors
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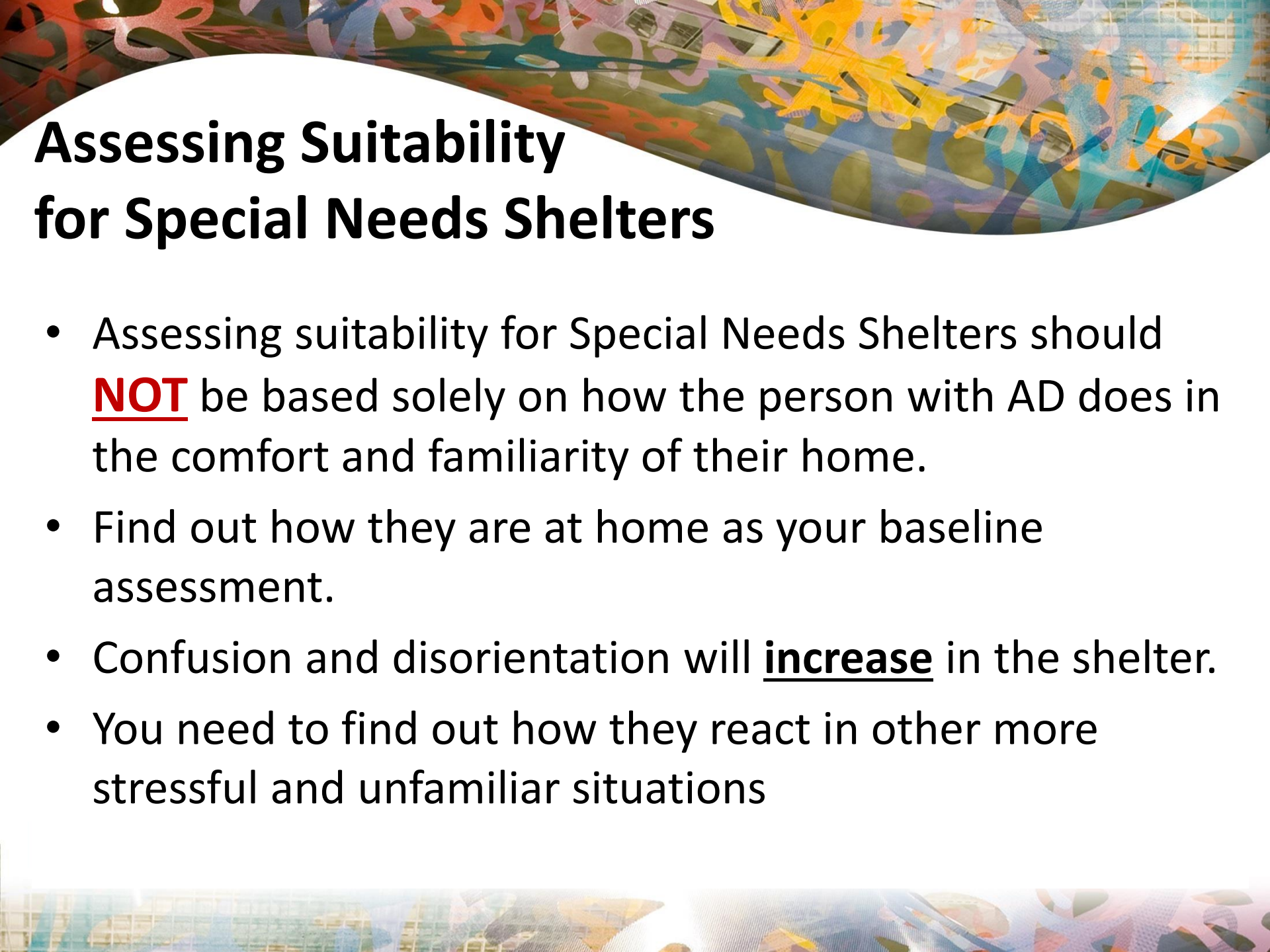


Supporting Alzheimer's Caregivers

- Caring for a person with Alzheimer's is overwhelming in the best of conditions
- Caregivers will be experiencing their own stress, worries and fears as well as having to deal with their loved one
- Caregivers will need reassurance, validation, comfort, compassion and a break if possible.



Part 4. Assessing Suitability for Special Needs Shelters



Assessing Suitability for Special Needs Shelters

- Assessing suitability for Special Needs Shelters should **NOT** be based solely on how the person with AD does in the comfort and familiarity of their home.
- Find out how they are at home as your baseline assessment.
- Confusion and disorientation will **increase** in the shelter.
- You need to find out how they react in other more stressful and unfamiliar situations



Baseline Questions

- How is their mood most of the time at home?
- Are they able to convey their needs verbally?
- Are they able to understand directions and conversation?
- Can they go to the bathroom independently?
- If not, how much assistance do they need?
- How is their walking and balance?
- Have they fallen recently? Is it a concern?



Baseline Questions

- Do they sleep through the night?
- Do they nap during the day?
- What do they do all day to keep occupied?
- Are they flexible, compliant and easy going or are they more rigid and difficult?
- Do they have problems with impulse control?
- Do they get frustrated easily?
- When you are home and they get upset or frustrated, what do they do?

Questions to Ask the Caregiver

- How often does your loved one go out to eat, go shopping, go to church?
- How do they react to crowds?
- How do they react to strangers?
- How do they react to excessive noise?
- How do they adapt to a change of plans and an unfamiliar place or routine?
- How are they affected by a lack of sleep?



Questions to Ask the Caregiver

- Have they ever wandered or tried to leave a place?
- Do they roam around the house and outside or are they comfortable in a small amount of space?
- Do they get agitated, angry or upset easily?
- If so, what makes them agitated or upset?
- Do they get agitated in unfamiliar places?
- Are you able to calm them down?
- When they get upset, or more confused do they ever lash out, hit or become defiant?



Questions to Ask the Caregiver

- Have they ever gotten verbally aggressive (yelling, name calling, screaming)? If so, what has caused the verbal aggression?
- Have they ever gotten physically aggressive (hitting, grabbing, kicking)? If so, what has caused the physical aggression?
- Do they experience hallucinations, delusions or paranoia? If yes, how does that affect their behavior and how do you handle it?



Part 5. Educating Caregivers about Special Needs Shelters



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Educating caregivers about shelters

- Educating Alzheimer's caregivers should be an on-going and yearlong process
- Information needs to be specific to Alzheimer's - not just for special needs shelters in general
- ***Information must explain the goals, reality and limitations of Special Needs Shelters
- Include checklist to help caregivers know if a special needs shelter is appropriate for their loved one.
- Explain that the person with Alzheimer's is the qualifying person for the special needs shelter.



Encourage Caregivers to Find Suitable Shelter

Make sure caregivers truly understand

- What a special needs shelter is and what to expect
- Extent of the help their loved one will receive
- Extent of help they will receive as the caregiver
- Dispel myths about medical personnel and staff at special needs shelter
- Limitations of special needs shelters



Encourage Caregivers to Find Suitable Shelter

- Do not be negative, but be honest
- Explain how the environment of the shelter might affect their loved one. They may be ok at home but the shelter is unfamiliar, crowded and loud.
- Ask if they have a relative or friend to stay with as a first option

Outreach Opportunities

- Outreach #1- pharmacies, adult day care, primary care, memory specialists, support groups to best reach AD caregivers
- Outreach #2- communities in evacuations areas.
- Outreach #3- senior centers, libraries, churches, clinics, food stores
- Articles in small neighborhood papers, TV interviews, senior publications

What to Bring

- Items familiar to the person with Alzheimer's
- Items to hold that are comforting- blanket, stuffed animal, pictures, religious items, favorite sweater etc.
- Favorite snacks (bring extra)
- Extra depends, clothes, and medicine
- Ask MD about medicines to calm them down
- Things for them to do. (magazines, game, coloring books, pictures, bible, stuff, etc.)



Questions?

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